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An analysis of the Research Team–Service User relationship from the Service User perspective: a consideration of 'The Three Rs' (Roles, Relations, and Responsibilities) for healthcare research organisations

Melanie Jordan PhD MA BA,* Emma Rowley PhD MSc BSc,† Richard Morriss MB ChB MMedSci MD FRCPsych‡ and Nick Manning BA MA MPhil PhD§

*Research Fellow, National Institute for Health Research CLAHRC-NDL, Nottinghamshire Healthcare NHS Trust & University of Nottingham, †Senior Research Fellow, NIHR CLAHRC East Midlands & Centre for Health Innovation, Leadership and Learning, Nottingham University Business School, ‡Professor of Psychiatry and Community Mental Health, Institute of Mental Health, University of Nottingham and §Director and Professor, Institute of Mental Health, Nottinghamshire Healthcare NHS Trust & University of Nottingham, Nottingham, UK

Abstract

Background This article debates interview data from service users who engaged with the work of a Collaboration for Leadership in Applied Health Research and Care (CLAHRC). The evidence base, to date, concerning the nature of CLAHRC work at the frontline (i.e. What is it actually like to *do* CLAHRC work?) is meagre; thus, this article represents an original contribution to that literature. Further, this article analyses service users' participation in research – as members of the research team – and so contributes to the body of developing literature regarding involvement too.

Objective This article explores the nature of the Research Team–Service User relationship, plus associated roles, relations and responsibilities of collaborative health research.

Design Qualitative social science research was undertaken in a health-care research organization utilizing interview method and a medical sociology and organizational sociology theoretical framework for analysis. Data utilized originate from a larger evaluation study that focuses on the CLAHRC as an iterative organization and explores members' experiences.

Results There can be a disparity between initial *expectations* and actual *experiences* of involvement for service users. Therefore, as structured via 'The Three Rs' (Roles, Relations and Responsibilities), aspects of the relationship are evaluated (e.g. motivation, altruism, satisfaction, transparency, scope, feedback, communication, time).

Correspondence
Melanie Jordan
National Institute for Health Research CLAHRC-NDL
Nottinghamshire Healthcare NHS Trust & University of Nottingham
Nottingham NG7 2TU
UK
E-mail: melanie.jordan@nottingham.ac.uk

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Regarding the inclusion of service users in health research teams, a careful consideration of 'The Three Rs' is required to ensure *expectations* match *experiences*.

Introduction

'User involvement has had an impact on research as well as becoming a subject of study' (p. 12).[1] Indeed, it is important to consider the outcomes of this form of involvement as well as the process itself; this article explores the process. Further, 'patient or consumer involvement in research is widely recommended, but although guidelines for researchers and patients have been produced, few practical experiences have been published and involvement remains fragile' (p. 676).[2] This article adds both to this small body of literature exploring service users' participation in the research endeavour and the evidence regarding the fragility of this form of research involvement.

The article debates interview narratives from service users who have engaged with the work of the CLAHRC research teams and the conduct of CLAHRC studies. England has multiple CLAHRCs. This study was conducted at the National Institute for Health Research (NIHR) CLAHRC for Nottinghamshire, Derbyshire and Lincolnshire (NDL). The CLAHRC represents an applied, multidisciplinary and collaborative health-care research organization that seeks to address the health research evidence–health-care practice divide. The concept of service user will be explored in a following subsection; firstly, the aim of CLAHRCs will be introduced.

An introduction to the Collaborations for Leadership in Applied Health Research and Care:

Currently, 'the limited extent to which research evidence is utilized in health-care and other public services is widely acknowledged' (p. 489).[3] In recognition of this incomplete involvement of research knowledge in health-care practice, the National Institute for Health Research (NIHR) funded nine CLAHRCs. These contemporary collaborative ventures are tasked with addressing the research–practice relationship and decreasing the gap between health-care evidence and health-care services, often referred to as Cooksey's second gap in translation.[4]

'Finding ways of translating research-based knowledge into health-care policy and practice has become one of the most pressing concerns over the last decade … In the wake of the current economic crisis arguments about wasted resources (in the form of funding for research whose outputs are not of practical use) and wasted opportunities (to implement cost-effectiveness health care) [these arguments] are even more pertinent' (p. 297, square brackets added).[5] Thus, 'CLAHRCs aim to carry out health research, implement research findings in local health-care organizations and build capacity across organizations for generating and using evidence' (p. 489).[3]

The implementation of evidence into routine NHS clinical practice is the intention of these relatively recently commissioned and fashioned organizations, via 'nurturing connections between those carrying out research and those responsible for delivering health care' (p. 490).[3] CLAHRCs are designed to coproduce research knowledge (i.e. joint working between NHS staff and academic staff, alongside patient and public involvement).

The CLAHRCs are titled collaborations. Accordingly, these collaborative organizations include numerous diverse social actors charged with dissimilar roles (health-care academic, service user, research clinician, health economist, research theme manager, *etc.*). Various forms of both experiential health-care knowledge and professional training are represented. This article explores the narrated experiences of several members of the organization who consider

themselves (current or ex) service users and who have engaged with CLAHRC research teams.

Rycroft-Malone *et al.*[6] highlight that the CLAHRCs are based on the idea that 'collaboration between academics and services might lead to more applicable health research that is actually used in practice' (p. 74); nevertheless, however, 'theoretically and intuitively appealing [this is] … the evidence for it is limited' (p. 74). This article develops the literature available in this field of collaborative health research practice.

An introduction to Patient and Public Involvement (PPI) in health-care research

PPI in health-care research is based on 'the idea that health knowledge comprises more than expertise gained through research and medical practice, because patients also have expertise gained through experience of living with an illness and receiving treatment' (p. 248).[7] Indeed, 'health research funders in the United Kingdom now ask applicants to state how their research will involve patients and members of the public' (p. 248).[7] A model is provided 'which places research and *expertise* at the centre of the involvement enterprise' (p. 248, italics not in original).[7] This approach focuses on the relevance and purpose of PPI in the research. It is suggested that patients and the public have expertise in the problems investigated by research that 'enables them to identify topics, question, populations, interventions and outcomes of importance' (p. 249).[7] Stewart and Liabo (2012) appeal for researchers to consider critically the areas of expertise of those involved in the research (including themselves) and where they are needed and apt in the research cycle – to develop the quality of the research.

Beresford and Carr (2012) explore both practical and theoretical issues in relation to service user involvement as 'there is growing interest in the impact of and outcomes from user involvement, as well as in its practice, theory and ideology' (p. 11).[1] Beresford and Carr (2012) argue this form of service user research involvement 'hinges on the nature of the knowledge produced and views experiential knowledge as generating a different and sometimes deeper understanding of the phenomena under investigation' (p. 122).[1] The subsequent analysis sections of this article address these aspects of knowledge validity plus the depth and scope of service user understanding.

Regarding public involvement in health research, Boote and Booth (2012)[8] conducted a literature review (covering 1995–2009). Mental health was the most common topic where health research included public participation. Together with qualitative research methods, participatory and action research were dominant approaches. In a numerical sense, relevant published studies peaked in 2006. Via this bibliometric review, there is evidence to suggest that health research is making positive progress in relation to public involvement. Nevertheless, Boote and Booth (2012) conclude with an appeal for improved dissemination regarding lay engagement. Reporting of public involvement work in articles' abstracts requires development. At present, this form of work within studies is rarely prioritized and devoted attention in abstracts and therefore often not included in reviews of this literature. This article therefore develops the body of literature that analyses this form of involvement in the health research endeavour. Increasingly, funding is available 'for those researching PPI itself, with studies exploring both the process and outcomes of PPI in research' (p. 248).[7] This article explores this novel avenue of inquiry.

The term PPI is not utilized in this article's subsequent analyses, as this phrase was not familiar with all participants and some disliked the label. Therefore, in accordance with the views and desires of participants, Service User as a term is used in this article – it was used and accepted by all interviewees. For clarity, these individuals were current or ex specific health service users (and not primarily public or caregiver involvement members).

Method

Data utilized for this article originate from a larger evaluation study of the CLAHRC-NDL that focuses on the CLAHRC as a developing organization and explores members' experiences of the 'research knowledge into practice' venture over the life course of the CLAHRC.

The CLAHRC-NDL recognizes 'conventional approaches to health research frequently generate evidence in isolation from the environment in which it is intended for use' (p.1),[9] and thus, both professional and patient perspectives are embraced in the knowledge mobilization and knowledge coproduction pursuits of the CLAHRC-NDL organization.[9] Therefore, the overall project involves dissimilar interview sample groups from across the organization's membership (researchers, board members, ex-staff, principal investigators, service users, clinicians, managers, *etc*.).

The study involves forty-six semi-structured interviews from across one CLAHRC's membership. Myriad CLAHRC clinicians, academics, managers and all formally listed members of research teams were invited to take part in the study. Interviews took place at NHS sites, participants' homes and in various university buildings. Approved participants information sheets and consent forms were used. The interviews were recorded and then transcribed verbatim. Interviews lasted between half an hour and three hours. All interviews were conducted by the same interviewer. This individual also led the analysis, using the software NVivo. Grbich (2007) considers the process of thematic analysis to consist of two complementary data reduction techniques: block and file, and conceptual mapping (pp. 32–35). Both of these disparate yet complementary processes were utilized in this study. Developing analytical themes were debated with the research team and the Analysis Reference Group. This article analyses, and intentionally prioritizes, the service user voice. Data from other study participants are debated elsewhere; this short article cannot represent all interviewee groups.

The nature of the discussions in this article is slightly unusual, as *individual* service users debate their experiences of social *groups* (i.e. research teams). This somewhat unorthodox approach – that does not focus on individualized person-to-person relationships, but instead individual social actor membership into a group relationship – was an intentional aspect of the study design. Had these service users been asked in the interviews to discuss their relationships with individual CLAHRC members of staff, it may not have been possible to anonymize these data for publication or further learning opportunities for the CLAHRC and the wider health research community.

It is also worth noting that the service user interviewees engaged with different research teams from across the health-care research organization; debates therefore do not relate to only one CLAHRC research team.

Service user involvement in the study's analysis

Sweeney *et al.*[10] debate service user researchers and qualitative collaborative data analysis. Sweeney *et al*. (2012) commence by highlighting 'health research is frequently conducted in multidisciplinary teams, with these teams increasingly including service user researchers … [however] it is less common for service user researchers to be involved in data analysis and interpretation' (p. 1). Thus, Sweeney *et al*. (2012) conducted a study that utilized a multiple coding technique 'to understand and explore differences and to build multidisciplinary consensus' (p. 1). It is argued that multiple coding represents 'an important means of hearing service users' voices in qualitative data analysis' (p. 1). However, notwithstanding the overall positives, it is crucial to recognize and remember that a service user's voice may be overwhelmed in the process of multiple coding as it so heavily relies on the research team's willingness to listen, debate and concede.

This CLAHRC study held an Analysis Reference Group between the research team, CLAHRC PPI reps and additional researchers from the CLAHRC implementation research theme. Analytical discussions from the Analysis Reference Group developed both the catalytic validity of the project and fed into the development of this article. The Group's members are thanked for their input.

Results and discussion

To summarize, the service user members of research teams were asked in the interviews to reflect on why they joined the specific health study and the overall organization – the CLAHRC – and then their subsequent experiences of involvement. Interviewees report a desire to dedicate time to the research process and that their input be validated by the research team. Overall, service user health knowledge is understood as warmly welcomed and valued by the wider research teams. Further, these service users highlight the importance of flexibility in research (i.e. that research plans and teams should have the scope to alter the study as a result of service user advice). Overall, however, expectations can be seen as not always aligning with experiences (e.g. lack of frequent communication). Findings highlight multiple concepts for debate including altruism, surprise, motivation, satisfaction, transparency, scope, feedback and time.

Therefore, attention is now devoted to in-depth analyses of these findings via examining the Research Team–Service User relationship – as structured via 'The Three Rs' (Roles, Relations and Responsibilities) and informed by the medical sociology and organizational sociology literature.

The predominant themes from the analysis process have been selected for inclusion below, and explanatory interview quotes are utilized to support the discussion. No ID numbers or pseudonyms accompany the interview excerpts; this is to ensure the anonymity of participants and ensure links between quotes do not exist that may identity the service user.

'The Three Rs'

R no. 1: Roles

Motivations. Interviewees were asked to reflect on their personal motivations and reasons for joining a CLAHRC research team and what they anticipated their role with the CLAHRC to be like. Desire for engagement was linked to:(a) an expected significant time dedication to the role,(b) a predicted sense of satisfaction from team membership,(c) an anticipated valid contribution as a result of experiential knowledge.

To illustrate, three specific motivators are debated below.

Narrated motivations for involvement often demonstrate an altruistic element; a desire to be useful without expectation of personal reward:

> I'm particularly interested in X [e.g. cancer] research, not necessarily for what it does for me, but what it does for fellow X survivors.

> I've got … a working mind and time … and knowledge, I suppose, I mean experience. So I want people to use it basically, I want people to use, to make use of it. I think that's quite important.

> I want to be useful … I'm passionate that I want what I'm doing [for the CLAHRC] to be useful.

N.B.

Within the interview excerpts, *X* is used to replace identifying details that have been removed to uphold confidentiality and anonymity. All comments in square brackets have been added by the lead author. Ellipses denote removed sections.

Links between altruism and the research endeavour are well documented. For example, Geller *et al.*[11] debate women's participation in breast cancer susceptibility testing protocols, plus motivators for their involvement in these tests. Motivational differences between the general population and the clinical population (i.e. those considered high risk because they had more than one relative on the same side

of the family with early-onset breast cancer) are analysed. Overall, those from the general population displayed 'an altruistic desire to help research [that] was a greater motivator for participation than interest in being tested' (p. 377).

Rowley (2007)[12] highlights that genetic testing decision making can be experienced as a moral issue and thus influenced by an individual's perceived need to be '*seen* to be protecting their relatives' (p. 244) – in a public manner via undergoing and reporting tests and their results. The notion of visibility is raised here also, as desire to be involved with the research can also be linked with a desire to enact positive health-care change in a visible and palpable sense:

> I wanted to help make a difference so, you know, giving a perspective from a service user, if that helped, then I wanted to be involved.

> I'm quite passionate about wanting health-care research to be about what is likely to help patients, and actually make a difference to clinical practice in the real world.

Beresford and Carr (2012)[1] debate service user participation and argue: 'people want to get involved to exert an influence and to make change – personally and for others like themselves' (p. 29). Whilst the data from this study support the aforementioned change desire for *others*, the notion of *personal* change is not included in this study's narratives; interestingly, the concept of personal change is absent from the interviews.

As an additional motivator that is present in the data, there is recognition that the health-care research organization is placed well to undertake this change work and engage service users in the collaborative process:

> My main aim is: As much as I can do to help people, to make them feel better, and help the people who do that [i.e. the CLAHRC researchers].

> The public are involved with their [i.e. the CLAHRC's] research so that lends us to have that voice.

Before joining the organization, participants perceived the CLAHRC as an apt and able vehicle to make use of, and value, service user knowledge.

Attention is now devoted to the experiences of these research team service users regarding their engagement with the CLAHRC studies. Campbell (2001)[13] debates the role of users of psychiatric services in mental health service development and argues 'issues about the how, when and where of involvement' arise (p. 87). Thus, it is to these issues we now turn. Campbell states:

> Most of the initiatives involving service users and service provides have been carried out under the banner of common interest. Working together, common concerns and partnership have been important words and phrases that have animated projects but helped conceal some of the realities – the different agendas and the imbalances of power(p. 88).[13]

Scope. Elberse *et al.*[14] explore patients' involvement in setting the research agenda for medical products and argue a dilemma can occur when attempting to find 'a balance between a predefined focus and being sufficiently broad to enable patients and patient representatives to contribute' (p. 231). Interview narratives for this study also debate this concept of scope, the service users' role here, and the feasibility and flexibility of studies to respond to suggestions:

> I always thought research was about exploring new frontiers for the benefit of progress and I felt [the] research was not radical enough in key areas ... So I'm being a bit too critical in saying that they [the research team] didn't really take it on-board, I think they did, but I don't think the research project gave them the time to say 'hey this is somewhere where we should go!'. Do you know what I mean? I got, err, 'it's something for another day' or of that ilk, so that tells you yes it's interesting but no not for this project.

However, service users can play a scope-orientated role; Nierse *et al.*[15] demonstrate service user involvement 'contributed to a research agenda which was not just a dry

enumeration of research topics and questions, but encompassed a more holistic perspective that was recognizable for patients with [the specific illness]' (p. 250).

Regarding possible barriers to full involvement at the beginning of the research process, Hewlett *et al.*[2] analyse patients altering their roles to become research partners (and thus meeting with health-care professionals as colleagues and not as patients) and observe 'it was some of the professionals who were more challenged by these varying relationships' (p. 677). It is crucial to remember that this Service User–Research Team relation can be novel for researchers too.

To return to the notion of scope, Nierse *et al.*[15] argue this form of involvement in the research process can produce new and unexpected outcomes; thus, in relation to this article, it leads to a supplementary question: Do research Principal Investigators desire this element of the unknown? In addition to this researcher desire element, Staley *et al.*[16] discuss challenges faced by organizations where patients are included in the research priority setting process and argue this form of involvement can create 'unrealistic expectations' (p. 8) in relation to limited budgets and research capacity restrictions. Discordance between service users' expectations and outcomes regarding the research process is raised here: research expected as revolutionary vs. research experienced as incremental development only.

'The Three Rs'

R no. 2: Relations

Experiences. Regarding the experiences of service users who worked on research teams, a certain degree of surprise was evident at (a) the validity ascribed *to*, and (b) the preceding relative absence *of*, their experiential knowledge regarding health services:

> I was surprised, I thought that anything I'd say would be obvious, given that they research the area, but I think it's not always the case because it's, obviously, from a service user perspective.

Both service user experience and first-hand knowledge of health interventions, as brought to the research team and the collaborative research work, are considered worthy and appreciated by the teams' members.

Notwithstanding this positive finding, as the seminal work of Turner (1995)[17] highlights, relations between social knowledge and medical power can be problematic and convoluted. For example, the relationship between clinical professions and their knowledge and power bases are perpetually debated in the field of medical sociology. Indeed, Turner (1995) demonstrates how the patient–clinician association can be analysed in relation to: the maintenance of professional knowledge boundaries by clinicians; power over realm of practice by clinicians and associated workplace roles and responsibilities; the maintenance of professional body prestige; monopolization of health and illness definitions; concerns regarding deskilling and fragmentation of the occupational group.

However, service user interviewees in this study provide examples that for them, and the team, demonstrate their nature of involvement as not tokenistic, where input is instead perceived as beneficial and meaningful:

> They treat me with respect, they value what I say, they listen to me, and they ask me for my views … It makes me feel like, I am, I can actually make a difference and I am actually useful; not just a kind of, um, a token service user that's supposed to be in place.

The service users who participated in this study considered their health knowledge to be labelled both worthy and welcome within their relevant CLAHRC research teams.

Further, satisfaction via involvement is evident in these service user interview transcripts:

> I really enjoy what I'm doing here.

> I like being involved with the study and I'm a great believer in the X study.

Further to this satisfaction, the notion of team membership is raised by participants and

the feeling of being a member of a shared collaborative piece of work is experienced:

> I do feel part of the team.

> I helped with that study and I've been involved all the way through.

> I wasn't left out, I felt fully part of the team.

However, Hewlett *et al.*[2] discuss patients as research partners and argue one of the challenges to full contribution is the influential role played by informal and unplanned communication in the workplace amongst research colleagues (e.g. 'corridor meetings' p. 676). This may – albeit perhaps unintentionally and unknown to service users – be exclusionary practice regarding service user involvement, as these members of the team are not often located full time in the place of the *informal* research work and are often only invited to join the research team at the *formal* meetings.

The following two subsections highlight areas for potential improvement regarding the conduct of collaborative research.

Communication. Service users involved in this study desire additional communication from their CLAHRC research team colleagues:

> It seems a long time since I've had any communication.

Further, this perceived lack of communication can result in an experienced lack of knowledge regarding the study that is considered regrettable:

> I was so excited by this project … I really thought it was going to go somewhere, and it may have, I don't know.

> I get an odd email now and again from the lead saying we must catch-up, we must keep you in touch but never, never happens so, err, I don't know why, don't know why.

An additional element includes the allocation of tasks, but then not receiving the work:

> I was always being asked to comment on draft work but never received any [to review].

Campbell (2001)[13] argues 'when service users are always invited but never invite, the true nature of partnership must be questioned' (p. 88). This statement gains significance here, as service users do not invite to the research teams but are, additionally, also on occasion invited to undertake tasks but then not always provided with the work – once again causing somewhat of a mismatch between the expectations of involvement and its reality.

Time. Thus far, the term problem has not been utilized in this article. However, with regard to researchers' time, this phrase is used in the interviews by participants and so it is in this subsection:

> But one of the problems is time.

> [Their] time is a problem.

> Not enough time [for the academics], I know what time at night the emails come.

To link the issues of time and communication, there exists an absence of *expected* communication in tandem with *assumed* time constraints:

> Research leads were always keen to meet and discuss key points recommended, but [this] never happened, it was as if they were too busy.

The perceived lack of researcher time is markedly contrasted with the service users' depiction of their time and availability:

> I suppose I feel that I'm not being used enough.

> It might be because they feel that they don't, that they shouldn't take up my time or, or whatever. No, it's available … I've got plenty of time.

> I'm retired. I've got time.

As an extreme interview narrative example regarding this notion of time, (lack of) time is

experienced as an important reason in the eventual breakdown of the Service User–Research Team relationship:

> Key personnel were very overstretched and I think that is why, err, there was a failure between myself and them.

Poignantly, this reraises the motivations and expectations of involvement with which this article began. It also poses the question: Do researchers devote sufficient time to service user involvement in the research process, and are researchers provided with sufficient time to undertake these roles?

'The Three Rs'

R no. 3: Responsibilities

Transparency

> My understanding of the CLAHRC as a whole is hazy.

A sense of CLAHRC-related opacity pervades the interview transcripts. The organization is not experienced by these members as clear or transparent.

Ambiguity is felt in relation to CLAHRC roles and responsibilities, plus the nature of the organization as a whole – including its set-up, hierarchy, strategy, aims. The CLAHRC is narrated as a somewhat occluded and impervious entity.

For example, a perceived lack of explanation exemplifies this facet further:

> Nobody ever explained to me what the CLAHRC was.

> No explanation was given to me by anybody ... It was just, join the meetings, and that was it, really.

The absence of agreed definitions regarding the nature of involvement is also evident:

> No clear role, no clear definition of what a service user is supposed to do.

> I was self-teaching myself on what the role should be.

As a result, something akin to a job description is suggested:

> This is what you are, this is what you're for. This is the role you have in relation to the research project. This is the amount of clout you have.

Hewlett *et al.*[2] also report anxiety for patient research team members where an absence of clarity regarding role is experienced and highlight this is similar 'to those of anyone moving into a new field of work' (p. 677).

Nevertheless, fixed descriptions could be considered constraining, which is arguably problematic for a novel health-care research organization that is intended to embrace innovation, continually reflect and learn, plus develop iteratively across its lifespan.

Notwithstanding the importance attached to *service users'* understandings regarding roles and responsibilities, this desired clarity is extended to the *team members* too; a consensual understanding regarding the remit of the service user research team member is sought:

> But much more important is that they [the researchers] understand.

To further exemplify the nature of this role ambiguity, one interviewee suggests the CLAHRC – as an organization – should reconsider the following:

> What would this facility like to see from service users?

Faulkner[18] suggests an apt framework for service user participation is the facilitation of purpose, presence, process and impact. This four-stranded approach to involvement would also likely address this issue of the transparency.

Feedback. Hewlett *et al.*[2] list considerations for this form of research partnership and stress the importance of facilitating inclusion and contribution and argue research teams

must question whether the expertise of the ex-patient and now research colleague is being recognized aptly (via, for example, swift feedback). Emphasis added to the quotes below illustrate the following service users are on occasion left to assume their involvement is appreciated and can experience a lack of feedback:

> I think X [the study's PI] and the team were very happy that I was doing that.

> They appeared to be very grateful for the comments.

> We could make recommendations, but were they ever put into effect?

> I'm just assuming that they invite me again because I was all right last time.

Feedback should be considered standard practice in this form of collaborative research.

Conclusion

Health-care research organizations that implement a collaborative approach to the research endeavour and involve service users in research teams arguably ought also to accept the accompanying roles and responsibilities of this practice, and increasingly consider how the relationship is experienced by the service user research team members. This article argues the motivations, and most importantly the *expectations*, of services users regarding their inclusion in the research should be the very starting point for the relationship and discussions for the research team – so that the roles and responsibilities of the service users and of the researchers, pertaining to this relationship, are crafted by the team (but also understood by and agreed to across the whole research team) from the outset. This is arguably a crucial collaborative construction process for such research teams, as a mismatch between *expectations* and *experiences* for service user team members can result in disillusionment and occasionally complete disengagement with the study and even the wider health-care research organization.

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